



DEPARTMENT OF HEALTH AND HUMAN SERVICES

Health Resources and Services Administration

Meeting of the Advisory Committee on Heritable Disorders in Newborns and Children

AGENCY: Health Resources and Services Administration (HRSA), Department of Health and Human Services.

ACTION: Notice.

SUMMARY: In accordance with the Federal Advisory Committee Act, this notice announces that the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC or Committee) has scheduled a public meeting. Information about the ACHDNC and the agenda for this meeting can be found on the ACHDNC website at <https://www.hrsa.gov/advisory-committees/heritable-disorders/index.html>.

DATES:

- Thursday, November 3, 2022, from 9:30 AM - 3:00 PM Eastern Time (ET); and
- Friday, November 4, 2022, from 9:30 AM - 1:00 PM ET.

ADDRESSES: This meeting will be held in-person and via webinar. The address for the meeting is 5600 Fishers Lane, Rockville, Maryland 20857. While this meeting is open to the public, advance registration is required. Please register online at <https://www.achdncmeetings.org/registration/> by the deadline of 12:00 PM ET on November 2, 2022. Instructions on how to access the meeting via webcast will be provided upon registration.

FOR FURTHER INFORMATION CONTACT: Alaina Harris, Maternal and Child Health Bureau, HRSA, 5600 Fishers Lane, Room 18W66, Rockville, Maryland 20857; 301-443-0721; or ACHDNC@hrsa.gov.

SUPPLEMENTARY INFORMATION: ACHDNC provides advice and recommendations to the Secretary of the Department of Health and Human Services (Secretary) on the development of newborn screening activities, technologies, policies, guidelines, and programs for effectively

reducing morbidity and mortality in newborns and children having, or at risk for, heritable disorders.

The ACHDNC reviews and reports regularly on newborn and childhood screening practices, recommends improvements in the national newborn and childhood screening programs, and fulfills requirements stated in the authorizing legislation. In addition, ACHDNC's recommendations regarding inclusion of additional conditions for screening on the Recommended Uniform Screening Panel (RUSP), following adoption by the Secretary, are evidence-informed preventive health services provided for in the comprehensive guidelines supported by HRSA pursuant to section 2713 of the Public Health Service Act (42 U.S.C. 300gg-13). Under this provision, non-grandfathered group health plans and health insurance issuers offering non-grandfathered group or individual health insurance are required to provide insurance coverage without cost-sharing (a co-payment, co-insurance, or deductible) for preventive services for plan years (i.e., policy years) beginning on or after the date that is one year from the Secretary's adoption of the condition for screening.

During the November 3-4, 2022, meeting, ACHDNC will hear from experts in the fields of public health, medicine, heritable disorders, rare disorders, and newborn screening. Agenda items include the following:

- 1) A presentation on phase two of the Krabbe disease evidence review,
- 2) A presentation on the Department of Defense's newborn screening system,
- 3) A presentation on the process for states to implement conditions recently added to the RUSP,
- 4) A presentation on Blueprint for Change for a system of services for children and youth with special health care needs (see <https://mchb.hrsa.gov/programs-impact/focus-areas/children-youth-special-health-care-needs-cyshcn/blueprint-change>),
- 5) A Committee discussion on advancing state newborn screening systems,
- 6) Workgroup updates, and

- 7) A potential update on the Duchenne muscular dystrophy condition nomination and a potential vote on whether to move it forward to full evidence-based review.

The agenda for this meeting includes a potential vote the Committee may hold on whether or not to recommend a nominated condition, Duchenne muscular dystrophy to full evidence-based review, which may lead to a recommendation to add or not add this condition to the RUSP at a future time. In addition, as noted in the agenda items, the Committee will hear a presentation on the evidence review of Krabbe disease, which may lead to such a recommendation to add or not add this condition to the RUSP at a future time.

Agenda items are subject to change as priorities dictate. Information about the ACHDNC, including a roster of members and past meeting summaries, is also available on the ACHDNC website.

Members of the public also will have the opportunity to provide comments. Public participants may request to provide general oral comments and may submit written statements in advance of the scheduled meeting. Oral comments will be honored in the order they are requested and may be limited as time allows. Requests to provide a written statement or make oral comments to the ACHDNC must be submitted via the registration website by 12:00 PM ET on Thursday, October 27, 2022.

Individuals who need special assistance or another reasonable accommodation should notify Alaina Harris at the address and phone number listed above at least 10 business days prior to the meeting. Since this meeting occurs in a federal government building, attendees must go through a security check to enter the building. Non-U.S. Citizen attendees must notify HRSA of their planned attendance by contacting ACHDNC@hrsa.gov no later than October 12, 2022, in order to facilitate entry into the building. All attendees are required to present government-issued identification prior to entry.

Maria G. Button,

Director, Executive Secretariat.

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